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which has been published in final form at

<https://doi.org/10.1016/j.pec.2018.11.001>

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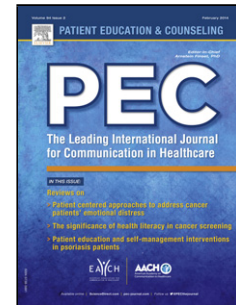
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## Accepted Manuscript

Title: What are the components of effective chronic condition self-management education interventions for children with asthma, cystic fibrosis, and diabetes? A systematic review

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PII: S0738-3991(18)30969-8  
DOI: <https://doi.org/10.1016/j.pec.2018.11.001>  
Reference: PEC 6115

To appear in: *Patient Education and Counseling*

Received date: 22 March 2018  
Revised date: 24 September 2018  
Accepted date: 5 November 2018

Please cite this article as: Saxby N, Beggs S, Battersby M, Lawn S, What are the components of effective chronic condition self-management education interventions for children with asthma, cystic fibrosis, and diabetes? A systematic review, *Patient Education and Counseling* (2018), <https://doi.org/10.1016/j.pec.2018.11.001>

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# What are the components of effective chronic condition self-management education interventions for children **with asthma, cystic fibrosis, and diabetes?**

A systematic review

**Title:** What are the components of effective chronic condition self-management education interventions for children **with asthma, cystic fibrosis, and diabetes?**

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## Highlights

- Effective education for children's CCSM exists; translation to practice is elusive
- Education should include sequenced curricula and active, problem-based learning
- Multiple exposures, feedback and reinforcement strategies are also valuable
- Different educational components are relevant to specific life stages
- Similar pedagogies were used across asthma, diabetes and cystic fibrosis

## Abstract

### Objective

To articulate the components of educational interventions that help children learn about managing their asthma, cystic fibrosis, or diabetes, relevant to their age/developmental status.

### Methods

A systematic review of chronic condition self-management (CCSM) educational interventions that included age/developmentally appropriate components, published before 27 January 2018, including evidence level and quality assessments. **Teaching approaches** were extracted and translated into practical components.

### Results

Twenty education interventions were identified, published across 30 studies. Most studies (n=20/30) were based on the theories of Piaget and Bandura. Similar **teaching approaches** were used across conditions, incorporating sequenced curriculum and a variety of active elements. Age/developmentally appropriate interventions resulted in improvements in the CCSM capabilities of children. Outcomes were improved when compared with usual care.

For very young children, educational interventions were directed at parents/families. As children reached school age, interventions increasingly became child-focused, promoting autonomy. Integrated play and reinforcement were common. Adolescent interventions placed greater emphasis on communication, problem-solving, and role division.

### Conclusion

Eight key components were identified: structured and sequenced curricula; reinforcement; active participation; collaboration; autonomy; feedback; multiple exposures; and, problem-solving. Different components are relevant to specific life stages.

## Practice implications

Clinicians require age/developmentally appropriate practical education tools to provide effective paediatric health care.

**Keywords:** self-management, children, adolescents, teaching approaches, education, asthma, cystic fibrosis, diabetes

## Main text

### 1. Introduction

Chronic conditions of childhood are common [1]. In Australia, asthma affects one in every 10 children, type one diabetes mellitus (T1DM) affects one in every 100 children, and cystic fibrosis (CF) **affects** 1 in every 2500 children [1, 2]. Together, these three conditions impact the Australian population more than any other childhood chronic conditions (i.e., high social, health service resource and financial costs) [1, 3]. With such high prevalence rates, it is almost inevitable that, over the course of a clinician's career, they will need to provide chronic condition self-management (CCSM) support to children.

Children's learning of self-management strategies, related to the ~~prevention and~~ management of their chronic condition, is associated with many positive outcomes. More specifically, childhood CCSM educational interventions have resulted in improvements in health outcomes, knowledge, quality of life, attendance at school, participation in social activities, and a decrease in health service interactions [4, 5]. CCSM educational interventions aim to empower children to be involved in their health care through the provision of information, teaching of skills and techniques, and reinforcing positive behaviours over time [6].

In their 2003 landmark article, Lorig and Holman [6] suggested that the effectiveness of CCSM educational interventions is maximised when they are designed to assist children and their families in setting goals, solving problems, and planning for positive health behaviours. Others have stated that educational interventions should be motivational, equipping the family unit (i.e., the child, their parents and siblings) with the knowledge, skills, and confidence they need to manage the daily demands imposed by the chronic condition [5]. **Despite the inclusion of these components, some interventions have failed to achieve their potential (i.e. demonstrate positive health outcomes) due to fact that children require different educational emphases as they develop self-management capacities over time [7].** Clark et al. [7] advocate for the use of developmentally appropriate program of educational content and tasks; a view that is supported by older systematic reviews and meta-analyses, which show that asthma self-management educational interventions are most effective when they are guided by evidence-based strategies, and a cognitively appropriate theoretical framework [4, 8].

While Australian and international clinical practice guidelines encourage age/developmentally appropriate CCSM education for children with asthma, T1DM, and CF, these guidelines lack a clear evidence base [9]. No published systematic reviews that look at age/developmentally appropriate CCSM educational strategies for children could be located. Unfortunately, paediatric clinicians may not be aware which teaching approaches represent good teaching practices for CCSM [9]. By allowing clinicians to access a CCSM educational toolbox that is

designed to suit children's ages and developmental needs (e.g., similar to what school teachers use in the classroom setting), health outcomes may be further improved.

### *1.1 Aims and objectives*

This systematic review aimed to articulate the components of effective educational interventions that help children learn about managing chronic conditions (i.e., asthma, diabetes and CF), relevant to their age/developmental status.

## **2. Material and methods**

The protocol for this review follows guideline recommendations, as set out in the 2009 PRISMA statement for systematic reviews and meta-analyses [10]. Due to a large amount of heterogeneity between CCSM educational interventions, a meta-analysis could not be performed.

### *2.1 Data sources and search strategy*

Studies were identified through an extensive search of medical databases: EBSCO (Medline, CINAHL, Biomedical Reference Collection, Nursing and Allied Health Collection, Psychological and Behavioural Sciences Collection, PsychInfo, SocINDEX), Elsevier (Embase) and Informit (Health sub-database). Search terms used were based on the National Library of Medical subject headings (i.e., MeSH terms) and included "asthma", "diabetes mellitus, type 1", "cystic fibrosis", "child", "adolescent", "self-care", "self-management" and "education" (<https://meshb.nlm.nih.gov/search>). To ensure that no studies of relevance were missed, the search strategy was supplemented with a review of citations listed for all included studies. Only studies published in English were eligible for inclusion.

### *2.2 Study selection*

Studies were included if they were published before 27 January 2018, and if they focused on children and adolescents (aged  $\leq 20$  years) with asthma, T1DM, or CF as active participants in the CCSM education strategy. Studies were excluded if they focused on adults, other childhood conditions, or if they did not contain age/developmentally based CCSM education components. A two-stage screening process was used to confirm studies that met the inclusion criteria. In stage one, studies were screened for relevance through title and abstracts, and duplicates were removed. Stage two excluded studies that did not consider age/developmental aspects of CCSM education. Furthermore, developing effective skills, attitude, and behaviours to manage their own health was the endpoint of this review; **therefore**, to be eligible, studies were required to report outcomes related to the following: children's CCSM skills, abilities, and behaviours; knowledge; cooperation and communication; sharing in decision-making; monitoring and

responding to symptoms; managing the impact of the condition; confidence in managing their condition (self-efficacy); **and** or quality of life.

The types of studies included in this review were not restricted; thus, a variety of different study designs, ranging from randomised control trials to pre-/post-cohort studies, were included. Descriptive studies were also included if they contained detail about the intervention educational strategy used, and if subsequent follow-up studies using the same education strategy provided outcome measurement data.

### 2.3 Data extraction

For studies meeting the inclusion criteria, the following data was extracted by the first author (NS) and confirmed by a second reviewer (SL):

- Detail about the interventional education strategy, including duration, mode of delivery, and other support mechanisms;
- Information about underlying developmental theories or age-based considerations, including **teaching** approaches (see section 2.3.1);
- Whether there was a manual/sufficient detail to reproduce the educational strategy;
- The setting (see section 2.3.2);
- Target age group/s (see section 2.3.3);
- Interventionist/s (see section 2.3.4);
- Training provided to the interventionist/s; and
- Relevant outcome data.

All information extracted was tabulated in a standardised evidence table [11]. Data extraction was not blinded to study author/s, year of publication, or journal.

#### 2.3.1 Age/developmentally appropriate theory, **teaching approaches** and **educational components**

There are many well-known theories of childhood development, including those proposed by Piaget, Erikson, Kohlberg, Bandura, Vygotsky, Kagen, Ausubel, and Gilligan [12]. Each included study (full text) was reviewed for any mention of developmental theory or age appropriate **teaching approaches**, or components that could be attributed to a distinct philosophy. As required, study authors were contacted to provide additional information about the age/developmental aspects and **teaching** approaches they included in their CCSM educational interventions. **Teaching approaches** used were subsequently classified into seven groups:



- (1) **Directive learning** (*i.e., involves the use of a structured evidence-based curriculum to teach skills and knowledge to children*)
- (2) **Active and experiential learning** (*i.e., acknowledge that learners come with many useful and relevant experiences; provides authentic hands on learning experiences*)
- (3) **Differential learning** (*i.e., activities address a range of learning styles, abilities and readiness; values differences between children*);
- (4) **Interactive play** (*i.e., uses tools such as games, art-based activities, puppets and competitive exercises to motivate children to learn better*);
- (5) **Integrated learning** (*i.e., learning brings together content and skills from more than one subject area*);
- (6) **Enquiry based learning** (*i.e., learning is directed by questions, problems or challenges that children work to address*); and
- (7) **Cooperative and peer learning** (*i.e., promotes learning with and from other children; group and cooperative learning strategies are a priority; provides opportunities for children to show their knowledge and skills*) [13].

### 2.3.2 Setting

Settings for CCSM education delivery were classified into three categories: (1) school; (2) community; and, (3) hospital.

### 2.3.3 Age groupings

According to the 1989 United Nations Convention on the Rights of the Child, childhood spans the ages of zero to 18 years [14]. However, in clinical practice, childhood can range from zero to the point at which children/adolescents are transferred to adult care (usually before the age of 20 years) [12]. Within this wide-ranging age span of zero to 20, and according to developmental theorists, there are several distinct stages of childhood [12]. Our review categories children into five groupings: (1) infancy - birth to two years; (2) early childhood - ages two to five years; (3) middle childhood - ages six to 11 years; (4) younger adolescents - ages 12 to 15 years; and, (5) older adolescents - ages 16 to 20 years.

### 2.3.4 Facilitators

Facilitators were classified into four groups: (1) health professionals; (2) teachers; (3) lay people; and, (4) social scientists. Where available, additional details about the facilitators were provided. For example, health professionals **might** be listed by discipline (e.g., doctors, nurses, credentialed educators, physiotherapists, and dietitians).

#### 2.4 Assessment of study design and quality

The strength of each study design was ranked according to the Australia National Health and Medical Research Council's (NHMRC) levels of hierarchy by the two reviewers [15]. Both reviewers also assessed the quality of studies using a modified version of the American Dietetic Association's quality assessment checklist for primary research (i.e., questions that directly relate to dietetic practice were expanded to cover a variety of health disciplines) [11]. When the reviewers did not agree on study design or quality rankings for individual studies, they undertook a discussion about this difference until an agreement was reached.

#### 2.5 Selection of key findings

**Eight key** educational components are presented in the **results and** discussion sections:

- (1) Structured and sequenced curricula
- (2) Reinforcement
- (3) Active participation
- (4) Collaboration
- (5) Autonomy
- (6) Feedback
- (7) Multiple exposures
- (8) Problem-solving

**Component selection** was based on the frequency **with** which the educational components were used in the included studies, as well as whether the components were evidence-based in educational settings.

#### 2.6 Ethics

This review includes data already published in peer-reviewed journals.

### 3. Results

#### 3.1 Search results

The search strategy yielded 4451 potential abstracts (including 14 studies identified through citations), from which 313 studies were retrieved for full-text review. Further screening excluded 283 studies for a variety of reasons. Overall, the search identified 20 age/developmentally appropriate CCSM educational strategies for 4406 children with asthma, T1DM, or CF, across 30 studies. Two studies used the same population group, which accounted for 167 shared participants [16, 17]. Figure 1 shows the search tree, including the reasons why studies were excluded.

A conservative screening approach ensured that the maximum numbers of studies were included, as it was often difficult to identify educational components that were based on developmental theories or age appropriate **teaching approaches**. The three most difficult challenges encountered by the authors, **during the process of** extracting data, were the multicomponent nature of each educational intervention, individual education components not articulated, and limited information provided about the developmental theories **upon** which the educational interventions were based.

### *3.2 General characteristics*

The 30 included studies were heterogeneous. Studies varied in population size (range 15 to 491 participants), focus condition (asthma  $n = 27$ , T1DM  $n = 2$  and CF  $n = 1$ ), and targeted age groups (infancy  $n = 1$  study, early childhood  $n = 3$  studies, school-aged children  $n = 24$  studies, younger adolescents  $n = 6$  studies, older adolescents  $n = 5$  studies, and adolescents of unspecified ages  $n = 1$  study). Several studies were designed to target more than one age grouping [18–23]. Furthermore, in regard to the country of origin, there was a disproportionately high number of studies conducted in the United States of America  $n = 20/30$  [18, 19, 23–39].

Most studies were conducted in schools ( $n = 19/30$ ), with only a small number of studies taking place in hospitals ( $n = 8/30$ ) [21–23, 27, 35, 39–41] and community settings ( $n = 4/30$ ) [29, 33, 34, 42]. Interventionists tended to be health professionals ( $n = 23/30$ ) and teachers ( $n = 4/31$ ). Prior training about the education interventions was provided to interventionists in 54% of cases.

The summary characteristics of included educational interventions can be seen in Table 1.

### 3.3 Age/developmentally appropriate theory, **teaching approaches** and educational components

**Twenty-one** of the 30 **included studies** mentioned **specific** developmental theories incorporated into their educational interventions for asthma, T1DM, and CF. Of these, Bandura's "Social Learning and Cognitive Theories" were routinely used, either alone  $n = 9$  [16–19, 33, 35, 39, 44, 45], or in combination with Piaget's "Cognitive Constructivist Theory"  $n = 12$  [24, 25, 27–32, 38, 41, 42, 46]. Influences from other theorists, including those of Ausubel and Vygotsky, were also apparent across the included studies.

Study authors used a range of teaching approaches and, thus, educational components:

- **Directive learning** ( $n = 25/30$  studies)
  - Directive learning was incorporated into CCSM educational interventions for asthma [16–22, 24–26, 28–34, 36, 39, 41, 44–46], and T1DM [35] through the use of structured and sequential learning curriculums.
- **Active and experiential learning** ( $n = 25/30$  studies)
  - Active and experiential learning was incorporated in interventions for asthma, [16–22, 25, 26, 28, 30–34, 36, 38, 39, 41, 44, 45] and T1DM [35]. Multiple exposures to CCSM skills training were evident in 10 studies [21, 22, 25, 28, 30–32, 38, 39, 46].
- **Cooperative and peer learning** ( $n = 21/30$  studies)
  - Cooperative and peer learning were incorporated in interventions for asthma [18–22, 24, 26, 28–34, 38, 39, 41, 46, 47] and T1DM [23, 35].
- **Interactive play** ( $n = 19/30$  studies)
  - Interactive play activities were included in asthma [16, 17, 24–26, 28–33, 36, 38, 41, 44–46] and T1DM [23] educational interventions. Play techniques were primarily used with school-aged children through the use of games, stories, videos, model building, and role-playing. Two studies also used role-playing in adolescent age groups [23, 46], and one study used play methods in children in the early childhood years [29].
- **Enquiry based learning** ( $n = 8/30$  studies)
  - Enquiry based learning was incorporated through practical demonstrations, problem-solving, and decision-making activities in asthma [11, 19, 20, 26, 33, 34, 36, 42] and T1DM [23] interventions.
- **Differential learning** ( $n = 3/30$  studies)
  - Differential learning was used in two asthma [21, 22] and one CF [27] educational intervention/s. All the interventions that used this particular **teaching approach** were targeted at adolescents (younger and older).
- **Integrated learning** ( $n = 3/31$  studies)

- Integrated learning was only used in asthma interventions. In two studies, asthma concepts were integrated into standard school curricula that were taught to all children in the class [34, 37]. In another study, how to use asthma inhalers was integrated into visual diagrams [40].

Reinforcement methods were used in almost all educational interventions ( $n = 26/30$ ), except for five studies [23, 27, 37, 39, 46]. **Table 2 provides specific details about the education components used for each age group.**

### *3.4 Age/developmental considerations*

For infants and very young children, educational interventions were directed at parents/families [29, 39]. As children reached middle childhood, interventions increasingly became child-focused and promoted children's autonomy [16, 17, 23–31, 33, 35, 36, 41, 42, 45, 46]. Integrated play and reinforcement were common for children in this age grouping [16, 17, 23–26, 28–33, 36, 38, 41, 44–46]. Adolescent interventions placed greater emphasis on communication, problem-solving, and role division [18–23, 34].

### *3.5 Study designs and quality rankings*

Randomised **controlled** trials (RCTs) accounted for the largest subgroup of literature published in this area ( $n = 20/30$ , 67%) [16–20, 23, 24, 26–28, 30, 31, 33, 35, 39, 41, 42, 44, 46]. Other study designs **included** clinical trials (not randomised) [21, 36, 37], and pre- and post-tests [25, 29, 34, 38]; these represented lower levels of evidence. This review also included two descriptive papers [21, 45] that were followed up with outcome data in subsequent studies.

The quality rankings of the included studies were mostly positive ( $n = 10/30$ , 33%), **or were** neutral ( $n = 14/30$ , 47%). There was good agreement between the two reviewers in regards to study design and quality rankings. Quality rankings of three studies [16, 17, 46] differed between the reviewers; however, a consensus was easily reached through discussion, and quality rankings for these three studies were later confirmed as being positive. There were no differences between the reviewers in the rankings of study designs.

### *3.6 Outcomes reported in the included studies*

Outcome measures used in studies were highly variable and not comparable. Furthermore, the length of follow-up (on completion of intervention to 24 months post-intervention), and the proportion of participants with complete follow-up (range = 50% to 100%), were mixed.

### 3.6.1 Intervention versus usual care

When the outcomes from education interventions with age/developmental considerations were compared to usual care, significant improvements arising from the former were seen across multiple domains (Table 3).

### 3.6.2 No comparison

Positive outcomes in children's CCSM skills, knowledge, confidence, and ability to manage their chronic conditions were also reported in the four observational pre-post studies [25, 29, 34, 38], and in the one RCT which did not report any control data [19].

## 4.0 Discussion and conclusion

### *4.1 Discussion*

This review synthesised data from 20 unique educational interventions with age/developmental considerations, published across 30 studies. Educational interventions were grounded in psychology, with most interventions being derived from the developmental theories of Piaget (Cognitive Constructivist Theory) and Bandura (Social Learning and Cognitive Theories). Influences from other theorists, including Ausubel and Vygotsky, were also apparent across studies. Teaching approaches included: directive learning (n = 25/30); active and experiential learning (n = 26/30); cooperative and peer learning (n = 26/30); integrated play (n = 19/30); enquiry based learning (n = 8/30); differential learning (n = 3/30); and, integrated learning (n = 3/30). Unfortunately, all of the reviewed interventions included multiple **teaching** approaches. Thus, it was not possible to attribute causality or effectiveness to any particular educational component. Nevertheless, identification of educational components was still achievable.

Positive study outcomes indicate that the children who took part in CCSM educational interventions that were tailored to be developmentally/age appropriate were more **able** to deal with everyday life. In the case of asthma, T1DM and CF, children and adolescents who participated in these tailored interventions knew more about their condition, and what they could do themselves to minimise the effects their condition had on them. **This was** demonstrated by significant improvements in knowledge [16, 18, 22, 24, 29, 34, 36, 37, 41, 42, 46], CCSM skills and abilities [18, 20, 23, 30, 31, 33, 35, 40, 41, 44, 46], and symptom monitoring and control [20, 28, 33, 35, 39], when compared to children receiving usual care in the included RCT studies. Some studies also showed significant improvements in children's ability to communicate openly about their condition with their peers, parents, and health professionals [23, 30, 31, 33, 35].

#### 4.1.1. Overarching concept – age/developmentally appropriate learning

The matching of **teaching** approaches to children's age/developmental stage was identified as an overarching concept in CCSM educational interventions. It is important that knowledge and skills are taught to the right level of complexity. Younger children appear to benefit from the use of interactive play and cooperative and peer learning in both the studies included in this review, and educational literature [48]. **Teaching approaches** that support deeper learning (and, thus, are more appropriate for adolescents) included collaborative learning and enquiry-based learning. The educational literature suggests that older adolescent learners are more likely to respond to **teaching approaches** that have genuine relevance to their own experiences [49, 50]. Clinicians should tailor educational interventions to the needs of infants, children in the early and middle years of childhood, younger adolescents, and older adolescents.

#### 4.1.2 Key findings – educational components

Children's CCSM education was found to be more than just imparting knowledge. Clinicians can best support children to develop CCSM skills, and mastery, by utilising multiple educational components.

The first key component that clinicians should include in children's CCSM educational interventions is '**structured and sequenced curricula**' (promoted in n = 26/10 studies) [16–22, 24–26, 28–36, 36, 39, 41, 44–46]. Lessons should be sequential, to build on skills previously mastered by children. Moreover, the structure of lessons should enforce daily CCSM routines. In his theoretical work on childhood development, David Ausubel stressed the importance of acknowledging and using the previous learnings of children [12]. Ausubel also advocated for learning to take place in meaningful ways, through disciplined organising and connecting of concepts [12]. The effectiveness of structured sequenced curricula is well proven in the educational literature, as demonstrated by large scale meta-analyses [49, 50].

Similar to proven adult models [51, 52], children's CCSM educational interventions need a varied curriculum. Topics to cover are: **K**nowledge of condition; children's active **I**nvolvement in their CCSM; **C**are plan; **M**onitoring and **R**esponding to symptoms; **managing I**mpacts of the chronic condition (e.g., physical, emotional and social impacts); **L**ifestyle aspects (e.g., diet and exercise); and **S**upport Services (e.g., parents, clinicians, teachers and community). An easy way for clinicians and children to remember these topic areas is through the use of the acronym **KIC-MR-ILS** [51, 52].

**'Reinforcement'** is the second most important key educational component (promoted in n = 26/30 studies). People facilitating children's CCSM educational interventions need to reinforce children's curiosity, problem identification (e.g., symptom monitoring), and problem-solving skills [53]. Methods such as children's demonstration of skills learned, debriefing at the end of sessions (children and parents), written support materials, take home CCSM action plans, and

homework activities were regularly included in the educational interventions. Homework activities seem to have been designed to provide children with the opportunity to develop further the CCSM skills they had just learned [53]. Evidence suggests that reinforcement strategies are important components of effective education [53, 54]. Research is sparse with regard to the importance of debriefing [53, 54].

**‘Active participation’** was identified as the third key component (promoted in  $n = 21/30$  studies which used active, experiential, and interactive play **teaching** approaches) [16–22, 25, 26, 28, 30–36, 38, 39, 41, 44, 45]. Children need to be active participants rather than spectators in the CCSM learning process. Active learning aims to provide authentic, experiential, and hands-on learning experiences [55]. The included studies acknowledged that learners needed time to interact with their peers and facilitators, as well as time to practice and adapt their newly learned CCSM skills. Active participation is a well-known evidence-based strategy for educating children and adolescents, and is promoted to teachers by government agencies [49, 50, 55].

The fourth key educational component was found to be **‘collaboration’**, and is inclusive of participation (promoted in  $n = 21/30$  studies) [18–22-24, 26, 28–35, 38, 39, 41, 46, 47]. Developmental theorist Lev Vygotsky was an advocate for the use of collaborative group activities to assist learning [56]. Ways that clinicians can promote collaboration include using teamwork activities (strategically choosing children that will work well together), and encouraging everyone to participate in the same learning task. According to the education literature, collaborative learning takes place when children actively participate in negotiating roles, responsibilities, and outcomes [49, 50]. In the educational setting, collaborative learning approaches are generally viewed as being effective, although effect sizes vary across studies [49, 50].

**The fifth** key educational component was learner **‘autonomy’** (promoted in  $n = 20/30$  studies) [16-23, 28-34, 36, 38, 41, 43, 44-46]. Jean Piaget’s belief that children are independent, and **that** development is guided by self-centred activities [12, 56], strongly influenced the design of most of the studies included in this review, as evidenced by almost all included studies being child or adolescent focused. Placing the child at the centre of the CCSM educational intervention acknowledges their growing autonomy, and allows them to be trained to assume a leading role in their condition management. It is also essential that clinicians support self-efficacy, as recommended by developmental theorist Albert Bandura, when promoting the autonomy of children and adolescents [12, 56].

**‘Feedback’** was identified as the sixth key educational component needed to deliver children’s CCSM programs [16-20, 28–32, 38, 39, 43-46]. A high level of facilitator-student interaction is required to teach children to be involved in CCSM, and feedback is critical. Feedback is important to both children with chronic conditions and facilitators, because it informs how progressing towards anticipated educational goals is going [55]. Timely feedback provides



opportunities for immediate correction and improvement. Feedback can be provided by a variety of people, including parents, educational facilitators, and peers. Methods of providing feedback can be oral or written, as long as the feedback includes specific advice that children can use to improve their CCSM skills. Appropriate feedback is a well-proven educational component for children and their teachers [49, 50].

Unexpectedly, '**multiple exposures**' was identified as the seventh key educational component (promoted in  $n = 10/30$  studies) [21, 22, 25, 28, 30–32, 38, 39, 46]. A well-cited educational article (> 70 citations) states that it takes, "three or four experiences involving interaction with relevant information for a new knowledge construct to be created in working memory and then translated to long-term memory" [57]. Multiple exposures are more than simple repetition or drill work [55]. They provide children with many opportunities to learn and practice CCSM skills, over time, through repeated learning opportunities [55]. Educational research demonstrates that multiple exposures have significant positive impacts on children being able to retain newly learned knowledge [49, 50].

The eighth key educational component was '**problem-solving**' (promoted in  $n = 8/30$  studies) [11, 19, 20, 23, 26, 33, 34, 36, 42]. Children with chronic conditions often face an uncertain, complex, and challenging future. Learning how to make well-informed decisions and solve problems can help children and adolescents better prepare for their futures [12, 56]. Collaborative discussion is a complementary strategy to problem-based learning. Research on problem-based learning has found that positive gains in knowledge are equal to, or better than, gains that employ a traditional lecture style instruction [58].

#### 4.1.2 Strengths and limitations of this review

This review addresses gaps in knowledge about children's CCSM educational interventions. While other paediatric research groups have identified and acknowledged the importance of CCSM educational components for children [59–61], this review marks the first time that components have been systematically classified. A well-recognised and structured process for conducting systematic reviews was followed [10]. Moreover, each of the included studies **was** assessed for evidence hierarchy level and quality by two reviewers.

Several limitations are also apparent. Firstly, only studies published in English were included. **Secondly, most of the included studies focused on asthma, which limits the generalisability of the findings of this review.** Thirdly, due to large heterogeneity between study parameters and outcomes measured, a meta-analysis could not be conducted. **Researches wishing to conduct future research in this area may wish to use the 2015 framework of CCSM outcomes by Sattoe et al. [62].** Fourthly, some studies might have not been included due to the reviewers experiencing difficulty when trying to identify studies that included age/developmental aspects of CCSM education (see section 3.1 for more

information). Lastly, it was impossible to attribute causality to individual education components because each of the included CCSM educational interventions used multiple **teaching** approaches.

#### *4.2 Conclusions and next steps*

Self-management education interventions that are tailored to a child's age/developmental stage help children with asthma, T1DM, and CF to develop effective skills, attitudes, and behaviours to manage their health. The effectiveness of these interventions was secured by including the following educational components: structured and sequenced curricula; reinforcement; active participation; collaboration; autonomy; feedback; multiple exposures; and, problem-solving. Different components are relevant to specific life stages. Further research is needed to be able to attribute causality and effectiveness to individual educational components. For example, research teams **could** consider conducting RCTs where the intervention group receives '**structured and sequenced curricula**' or '**reinforcement methods**', and the control group does not.

#### *4.3 Practice Implications*

Health professionals should educate children with a variety of chronic conditions using age/developmentally appropriate teaching approaches. **An additional contribution of this review was that it provides clinicians with the range of educational components that they can use to assist their young patients with learning CCSM. However, practical tools still** need to be developed to guide clinicians in how to do this.

#### *4.4 Acknowledgements and Declarations of Interest*

This review was supported by the following postgraduate scholarships (awarded to N Saxby) - Nursing and Allied Health Scholarship and Support Scheme and a Flinders University Research Scholarship. The authorship group has no conflicts of interest to declare.

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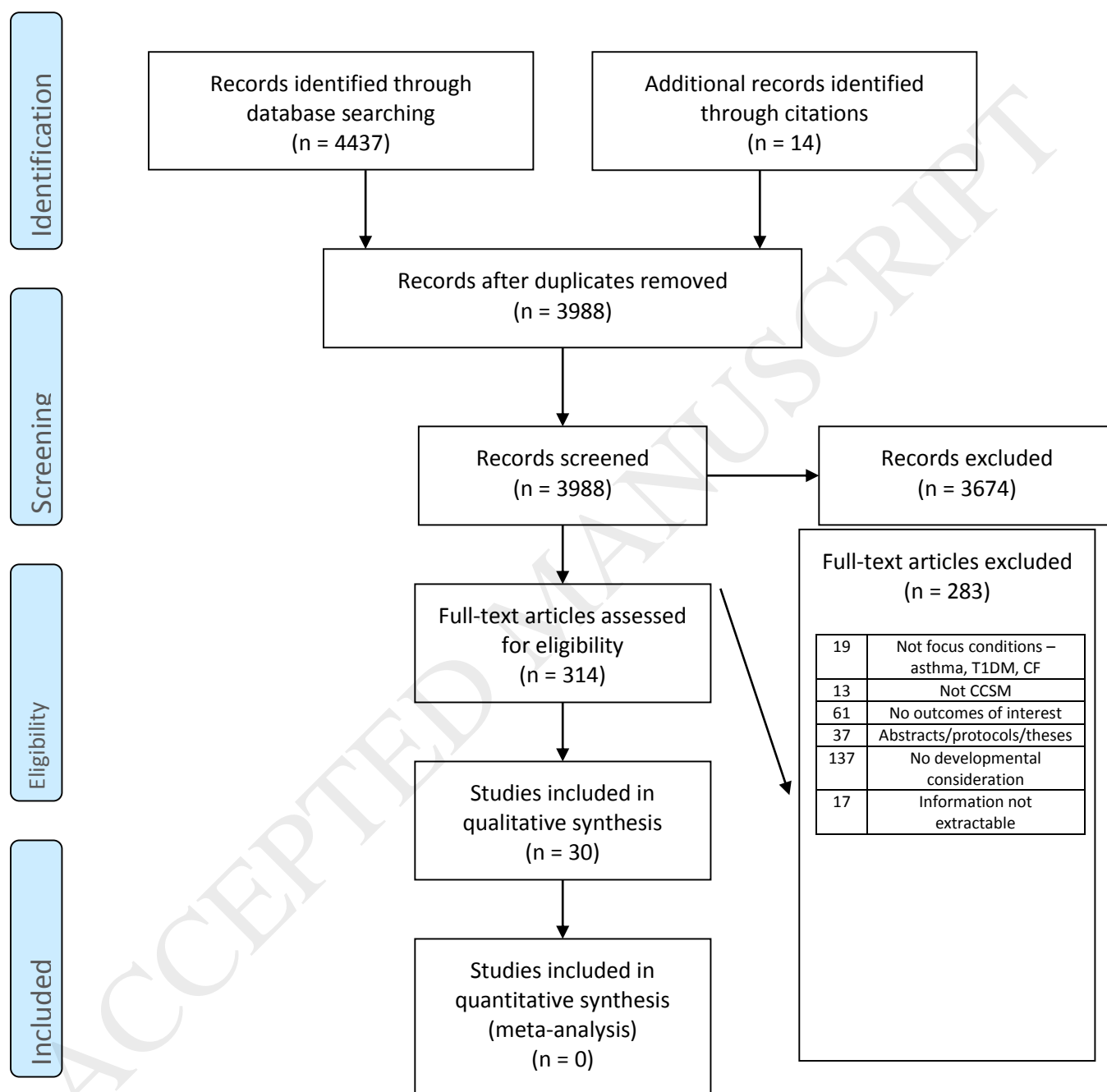
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**Figure 1** Search tree for age/developmentally appropriate CCSM educational interventions**PRISMA 2009 Flow Diagram**



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## Table

**Table 1** Summary characteristics age/developmentally appropriate CCSM educational interventions for children with asthma, CF, and T1DM

Intervention, Country	Study type, NHRMC ranking and quality (participants)	Underling developmental/ age-based theories	Description of CCSM intervention	Manual/detail to reproduce	Setting	Age group	Interventionist	Training provided	Relevant outcomes
<b>ASTHMA</b>									
'Asthma education program' [36]  United States of America (USA)	Parcel et al. 1980 Cross over cohort study III-30 (n = 104)	Unspecified	<ul style="list-style-type: none"> <li>Child- and family-centred</li> <li>24x 40-minute sessions for children               <ul style="list-style-type: none"> <li>Children and parents come together at the end of each session</li> </ul> </li> <li>Small groups (unspecified)</li> <li>Developmentally appropriate tool/s:               <ul style="list-style-type: none"> <li>Children's book "Teaching my parents about asthma" and concept related stories</li> </ul> </li> <li>Teaching approaches               <ul style="list-style-type: none"> <li>Directive learning</li> <li>Active and experiential learning</li> <li>Interactive play (stories)</li> <li>Enquiry based learning</li> </ul> </li> </ul>	YES	School	Middle childhood	Teachers and health professionals (psychologists, nurses)	NO	1980 (Parcel et al.) Following the 24-week program compared to controls: <ul style="list-style-type: none"> <li>↑ knowledge of younger† and older school children†</li> <li>↑ children's perception of having more control over their asthma†</li> <li>A trend towards ↓ in children's anxiety levels but NS</li> </ul>
'Asthma Care Training – For Kids' [33]  USA	Lewis et al. 1984 RCTII- (n = 76)	Bandura	<ul style="list-style-type: none"> <li>Child- and family-centred</li> <li>5x 60-minute sessions for children and parents               <ul style="list-style-type: none"> <li>Children and parents taught in separate groups for first 45 minutes of each session</li> <li>Children and parents come together at the end of each session</li> </ul> </li> <li>Small groups (4 to 7 children)</li> <li>Teaching approaches               <ul style="list-style-type: none"> <li>Directive learning</li> <li>Active and experiential learning</li> <li>Interactive play (games)</li> <li>Enquiry based learning</li> <li>Cooperative and peer learning</li> </ul> </li> </ul>	YES	Community	Middle childhood	Teachers, and health professionals (asthma educators, nurses, doctors)	NO	1984 (Lewis et al.) At 12 months compared to controls (non-developmentally appropriate lectures): <ul style="list-style-type: none"> <li>↑ compliance with CCSM tasks (children's self-report)*</li> <li>↓ impact of asthma symptoms (parent report)*</li> <li>↑ communication between children and their parents*</li> </ul> At 12 months for both intervention and control groups: <ul style="list-style-type: none"> <li>↑ children's positive beliefs about CCSM and asthma†</li> </ul>

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<p><b>'Open Airways for Schools'</b> [28, 30–32, 38, 43]</p> <p>USA</p>	<p>Evans et al. 1987 RCT II+ (n = 239) Homer 1998 Pre-post IV+ (n = 15) Spencer et al. 2000 Pre-post IV- (n = 364) Evans et.al 2001 RCT IIØ (n = 239) Bruzese et al. 2001 Pre-post IVØ (n = 54) Clark et al. 2004 RCT IIØ (n = 291)</p>	<p>Piaget and Bandura</p>	<ul style="list-style-type: none"> <li>• Child-centred</li> <li>• 6x 40-minute group sessions for children</li> <li>• Teaching approaches               <ul style="list-style-type: none"> <li>○ Directive learning</li> <li>○ Active and experiential learning</li> <li>○ Integrated play (stories, games)</li> <li>○ Cooperative and peer learning</li> </ul> </li> </ul>	<p>YES</p>	<p>School</p>	<p>Middle childhood</p>	<p>Social scientists and health professionals (unspecified)</p>	<p>YES</p>	<p>1987 (Evans et al.) At 12 months compared to controls (usual care):</p> <ul style="list-style-type: none"> <li>• ↑ children's CCSM skills†</li> <li>• ↑ children's self-efficacy†</li> <li>• ↑ children's influence on parental decision making†</li> <li>• ↑ children's number of actions taken by children in managing their asthma†</li> </ul> <p>1998 (Homer) Following 6-week program intervention group (pre-post):</p> <ul style="list-style-type: none"> <li>• ↑ children's knowledge†</li> </ul> <p>2000 (Spencer et al.) Following 6-week program intervention group (pre-post):</p> <ul style="list-style-type: none"> <li>• ↓ children's symptoms of asthma†</li> </ul> <p>2001 (Evans et al.) At 12 months compared to controls (usual care):</p> <ul style="list-style-type: none"> <li>• ↑ parents CCSM skills†</li> <li>• ↑ communication between child and parents re: CCSM†, which was associated strongly with parental CCSM skills</li> </ul> <p>2001 (Bruzese et al.) At 12 months compared to controls (usual care):</p> <ul style="list-style-type: none"> <li>• Children's communication was positively associated with parental self-management behaviours†</li> </ul> <p>2004 (Clark et al. 2004) At 24 months (pre-post) intervention group:</p> <ul style="list-style-type: none"> <li>• ↑ children's CCSM skills †</li> </ul>
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									At 24 months compared to controls (usual care):
									<ul style="list-style-type: none"> <li>• ↓ children's symptoms of asthma†</li> </ul>
'Modified Open Airways for Schools' [24]  USA	Bowen 2012 RCTII- (n = 32)	Piaget and Bandura	<ul style="list-style-type: none"> <li>• As above for Open Airways for Schools, with the following changes:</li> <li>• Program content synthesised into 3x 60-minute sessions</li> </ul>	NO	School	Middle childhood	Unspecified	Unspecified	2012 (Bowen) Following 3-week program compared to controls (usual care): <ul style="list-style-type: none"> <li>• ↑ children's asthma knowledge†</li> <li>• A trend towards higher QOL but NS</li> </ul>
'Huff and Puff' [29]  USA	Detwiler et al. 1994 Pre-post IV+ (n = 148)	Piaget and Bandura	<ul style="list-style-type: none"> <li>• Child- and family-centred</li> <li>• 3x 90-minute group sessions for children and parents</li> <li>• 2x 120-minute group sessions for parents</li> <li>• Teaching approaches               <ul style="list-style-type: none"> <li>○ Directive learning</li> <li>○ Active and experiential learning</li> <li>○ Integrated play (games, children's imagination, sensory involvement)</li> <li>○ Cooperative and peer learning</li> </ul> </li> </ul>	YES	Community	Early and middle childhood	Health professionals (nurses, doctors)	YES	1994 (Detwiler et al.) At 12 months (pre-post) intervention group: <ul style="list-style-type: none"> <li>• ↑ children's asthma knowledge†</li> <li>• ↑ children's CCSM ability in 4/5 items† (stop and rest, breathe slowly, relax, drink fluids)</li> <li>• ↑ children's confidence to manage their asthma†</li> </ul>
'The Roaring Adventures of Puff' [16, 17, 44, 45]  Canada	McGhan et al. 1998 Descriptive paper Cicutto et al. 2005 RCT IIØ (n = 256) McGhan et al. 2010 RCT II+ (n = 176) Mandhane et al. 2010 RCT II+ (n = 287)	Bandura	<ul style="list-style-type: none"> <li>• Child-, family- and teacher-centred</li> <li>• 6x 60-minute group sessions for children</li> <li>• 1x parent and teacher asthma awareness event</li> <li>• Teaching approaches               <ul style="list-style-type: none"> <li>○ Directive learning</li> <li>○ Active and experiential learning</li> <li>○ Interactive play (games, model building)</li> <li>○ Cooperative and peer learning</li> </ul> </li> </ul>	YES	School	Middle childhood	Health professionals (nurses, physios, health care students)	YES	1998 (McGhan et al.) – no outcome data 2005 (Cicutto et al.) At 2 months compared to controls (usual care): <ul style="list-style-type: none"> <li>• ↑ children's CCSM skills†</li> <li>• ↑ children's self-efficacy†</li> <li>• ↑ QOL†</li> </ul> 2010 (McGhan et al.) At 6 months compared to controls (usual care): <ul style="list-style-type: none"> <li>• ↑ parent's knowledge†</li> <li>• ↑ children's self-efficacy†</li> <li>• ↑ QOL†</li> </ul> 2010 (Mandane et al.) No significant results <ul style="list-style-type: none"> <li>• trends to improvement in QOL and parent assessment of child's symptoms</li> </ul>

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<b>'Young Children Managing Asthma' &amp; 'What's That Noise' [42]</b>  Australia	Holzheimer et al. 1998 RCT IIØ (n = 80)	Piaget and Bandura	<ul style="list-style-type: none"> <li>• Child-centred</li> <li>• Developmentally appropriate tool/s             <ul style="list-style-type: none"> <li>◦ Videotape 4 minutes long 'Young children managing asthma'</li> <li>◦ Picture book 'What's that noise?'</li> </ul> </li> <li>• Teaching approaches             <ul style="list-style-type: none"> <li>◦ Interactive play (stories)</li> <li>◦ Enquiry based learning</li> </ul> </li> </ul>	N/A	Community	Early childhood	Health professionals (unspecified)	NO	1998 (Holzheimer et al.) At 3 months compared to controls (usual care): <ul style="list-style-type: none"> <li>• asthma video and asthma book ↑ children's knowledge about condition†</li> <li>• asthma video only ↑ children's knowledge about condition†</li> <li>• asthma book only ↑ children's knowledge of condition†</li> </ul>
<b>'Wee Wheezers' [39]</b>  USA	Wilson et al. 1996 RCT IIØ (n = 76)	Bandura	<ul style="list-style-type: none"> <li>• Family-centred</li> <li>• 4x 120-minute group for parents</li> <li>• Teaching approaches             <ul style="list-style-type: none"> <li>◦ Directive learning</li> <li>◦ Active and experiential learning</li> <li>◦ Cooperative and peer learning</li> </ul> </li> </ul>	YES	Hospital (outpatient clinics)	Infancy, early childhood	Health professionals (nurses)	NO	1996 (Wilson et al.) At 1 month compared to controls (usual care): <ul style="list-style-type: none"> <li>• Reduction in child health morbidity†</li> </ul>
<b>'Asthma Self-Management for Adolescents Program (ASMA)' [19, 20]</b>  USA	Bruzzese et al. 2004 RCT IIØ (feasibility) (n = 45)  Bruzzese et al. 2011 RCT II+ (n = 345)	Bandura	<ul style="list-style-type: none"> <li>• Adolescent-centred</li> <li>• 5- to 8-week group sessions PLUS individual coaching sessions for adolescents</li> <li>• Teaching approaches             <ul style="list-style-type: none"> <li>◦ Directive learning</li> <li>◦ Active and experiential learning</li> <li>◦ Enquiry based learning</li> <li>◦ Cooperative and peer learning</li> </ul> </li> </ul>	NO	School	Younger and older adolescents	Health professionals (psychologists)	NO	2004 (Bruzzese et al.) Following completion of 8-week program (pre-post): <ul style="list-style-type: none"> <li>• ↑ understanding of the chronic nature of asthma (86%)</li> <li>• ↑ knowledge of asthma medications and controlling symptoms (100%)</li> <li>• ↑ knowledge of medication side effects and triggers (100%)</li> </ul> No control data reported 2011 (Bruzzese et al.) At 6 months relative to controls (usual care): <ul style="list-style-type: none"> <li>• ↑ adolescent self-efficacy†</li> <li>• ↑CCSM behaviours taking more steps to prevent symptoms at 6 months†</li> <li>• ↑ use of a written action plan†</li> </ul> At 12 months relative to controls (usual care): <ul style="list-style-type: none"> <li>• ↑ adolescent self-efficacy†</li> <li>• ↑ use of a written action plan†</li> </ul>

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<b>'It's a Family Affair Program'</b> [18] USA	Bruzzese et al. 2008 RCT IIØ (n = 24)	Bandura	<ul style="list-style-type: none"> <li>• Child- and family-centred</li> <li>• 6x 75-minute adolescent group CCSM education sessions</li> <li>• 5x 90-minute parental group sessions               <ul style="list-style-type: none"> <li>◦ Parental sessions focused on child rearing skills to support children's growing autonomy</li> </ul> </li> <li>• Teaching approaches               <ul style="list-style-type: none"> <li>◦ Directive learning</li> <li>◦ Active and experiential learning</li> <li>◦ Cooperative and peer learning</li> </ul> </li> </ul>	NO	School	Adolescents (unspecified)	Health professionals (psychologists)	NO	2008 (Bruzzese et al.) At 2 months compared to controls (usual care): <ul style="list-style-type: none"> <li>• ↑ adolescents knowledge of asthma†</li> <li>• ↑ CSSM beliefs (self-efficacy)†</li> <li>• ↑ positive CCSM attitudes and behaviours†</li> </ul>
<b>'Asthma 411 Initiative'</b> [37] USA	Pike et al. 2011 Clinical trial III-2- (n = 236)	Grade appropriate school curriculum	<ul style="list-style-type: none"> <li>• Child-centred</li> <li>• 15 standard school lessons</li> <li>• Teaching approaches               <ul style="list-style-type: none"> <li>◦ Integrated learning – asthma concepts included in 3 primary education subjects                   <ul style="list-style-type: none"> <li>▪ Math</li> <li>▪ Science</li> <li>▪ Communication arts</li> </ul> </li> </ul> </li> </ul>	NO	School	Middle childhood	Teachers	YES	2011 (Pike et al.) At the completion of program (pre-post) intervention group: <ul style="list-style-type: none"> <li>• ↑ knowledge - individual‡, combined students‡</li> </ul> Intervention vs. comparator group = differences were NS
<b>'Coping with Asthma at Home and at School'</b> [41] The Kingdom of the Netherlands	Colland 1993 RCT IIIØ (n = 195)	Bandura and Piaget	<ul style="list-style-type: none"> <li>• Child-centred</li> <li>• 10x 60-minute group sessions               <ul style="list-style-type: none"> <li>◦ Combination of CCSM training, cognitive behaviour therapy and developmentally based education</li> <li>◦ Parents invited for short periods each session</li> </ul> </li> <li>• Developmentally appropriate tool/s               <ul style="list-style-type: none"> <li>◦ Games designed to match developmental level of concrete operational thinking (asthma quarter, asthma quiz, asthma floor puzzle)</li> </ul> </li> <li>• Teaching approaches               <ul style="list-style-type: none"> <li>◦ Directive learning</li> <li>◦ Active and experiential learning</li> <li>◦ Interactive play</li> <li>◦ Cooperative and peer learning</li> </ul> </li> </ul>	YES	Hospital (outpatient clinics)	Middle childhood	Health professionals	NO	1993 (Colland et al.) At 6 months and 12 months follow-up compared to placebo and control groups: <ul style="list-style-type: none"> <li>• ↑ children's CCSM coping skills‡</li> <li>• ↑ children's CCSM knowledge‡</li> </ul>
<b>'Let's talk about asthma'</b> [34] USA	Mammen et al. 2017 Pre-post IV+ (n = 42)	Grade appropriate school curriculum	<ul style="list-style-type: none"> <li>• Adolescent-centred</li> <li>• 12-hour program, 4 sessions (delivered over 2 to 3 days)</li> <li>• Teaching approaches               <ul style="list-style-type: none"> <li>◦ Directive learning</li> </ul> </li> </ul>	YES	Community	Older adolescents	Health professionals	NO	2017 (Mammen et al.) Following 4 sessions (pre-post) intervention group: <ul style="list-style-type: none"> <li>• ↑ self-efficacy†</li> </ul>

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			<ul style="list-style-type: none"> <li>○ Active and experiential learning</li> <li>○ Integrated learning</li> <li>○ Enquiry based learning</li> <li>○ Cooperative and peer learning</li> </ul>						<ul style="list-style-type: none"> <li>• ↑ adolescent CCSM knowledge and problem solving skills‡</li> </ul> <p>Most significant effects were seen in: the awareness of long-term consequences of uncontrolled asthma, ability to recognise symptoms, correctly monitor symptoms and identify if asthma was uncontrolled</p>
<b>'Rural Children with Asthma – Interactive Educational Intervention' [26]</b>  USA	Butz et al. 2005[26] II RCT+ (n = 221)	Unspecified	<ul style="list-style-type: none"> <li>• Child-centred</li> <li>• 2x 120-minute sessions for children PLUS</li> <li>• 1 parental education workshop</li> <li>• Teaching approaches               <ul style="list-style-type: none"> <li>○ Direct learning</li> <li>○ Active and experiential learning</li> <li>○ Interactive play</li> <li>○ Enquiry based learning</li> <li>○ Cooperative and peer learning</li> </ul> </li> </ul>	N/A	School	Middle childhood	Health professionals (asthma educator)	NO	<p>2005 (Mammen et al.) At 10 months or a full school year compared to controls (usual care):</p> <ul style="list-style-type: none"> <li>• ↑ knowledge – parents ‡, children‡</li> <li>• ↑ child self-efficacy† (NS parents)</li> <li>• No significant differences seen in QOL measures</li> </ul>
<b>'Asthma Visual Mapping' [40]</b>  Iran	Bozorgrad et al. 2013 III-1- (n = 80)	Unspecified	<p>CCSM education to use asthma inhaler devices via the visual concept mapping (i.e., use of diagrams which are understandable to children without them needing the ability to read or write)</p> <ul style="list-style-type: none"> <li>• Use of pictures showing how to use spray 3 to 7 links</li> <li>• Prepared in 2 versions (boys and girls)</li> </ul> <p>Teaching approaches</p> <ul style="list-style-type: none"> <li>• Integrated learning</li> </ul>	N/A	Hospital (outpatients)	Middle childhood	Unspecified	NO	<p>2013 (Bozorgrad et al.)</p> <p>Immediately post-program relative to controls:</p> <ul style="list-style-type: none"> <li>• ↑ QOL†</li> </ul> <p>In the intervention group before and after the program:</p> <ul style="list-style-type: none"> <li>• ↑ activity‡</li> <li>• ↑ symptom awareness‡</li> <li>• ↑ emotional management‡</li> </ul>
<b>'Modular Education Program for Chronically Ill Children and Their Families (ModuS)' [21, 22]</b>  • This intervention can be	<p>Ernst 2016 Descriptive study</p> <p>Ernst 2017 Clinical trial III-1+ (n = 491)</p>	Unspecified	<ul style="list-style-type: none"> <li>• Child- and family-centred</li> <li>• 30x 45-minute sessions               <ul style="list-style-type: none"> <li>○ Separate curricular and didactic approach for children and parents</li> <li>○ 6 joint sessions for parents and children,</li> <li>○ 12 age appropriate sessions for children</li> <li>○ 12 sessions for parents</li> </ul> </li> <li>• Separate groups for different age groups</li> </ul>	YES	Hospital	Middle childhood, younger adolescents, older adolescents	Health professionals (paediatricians, psychologists plus other disciplines as required)	YES	<p>2016 (Ernst 2016) N/A</p> <p>2017 (Ernst 2017) Assessed in children with asthma. at 6 weeks both in the modular and conventional care programs delivered:</p> <ul style="list-style-type: none"> <li>• ↑ knowledge of families</li> <li>• ↑ QOL of children</li> <li>• ↑ life satisfaction</li> <li>• ↓ disease burden of families</li> </ul>

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altered to suit a variety of chronic conditions			<ul style="list-style-type: none"> <li>○ 6 to 12 years,</li> <li>○ 13 to 17 years</li> </ul>							When intervention group outcomes at 6 weeks were compared to controls, only children's reported asthma knowledge was significantly different.
Germany			<ul style="list-style-type: none"> <li>• Small groups (4 to 8 families)</li> <li>• Teaching approaches               <ul style="list-style-type: none"> <li>○ Directive learning</li> <li>○ Active and experiential learning</li> <li>○ Differential learning</li> <li>○ Cooperative and peer learning</li> </ul> </li> </ul>							
<b>'Children with Chronic Illnesses'</b> [46]	Tieffenberg et al. 2000 RCT IIØ (n = 188)	Piaget and Bandura	<ul style="list-style-type: none"> <li>• Child- and family-centred</li> <li>• 5x 120-minute sessions</li> <li>• Family reinforcement sessions at 2 and 6 months post-intervention</li> <li>• Teaching approaches               <ul style="list-style-type: none"> <li>○ Directive learning</li> <li>○ Active and experiential learning</li> <li>○ Interactive play</li> <li>○ Cooperative and peer learning</li> </ul> </li> </ul>	YES	School	Middle childhood, younger and older adolescents	Teachers	YES	2000 (Tieffenberg et al.) Asthma results only - At six months compared to controls (usual care):	<ul style="list-style-type: none"> <li>• ↑ knowledge†</li> <li>• ↑ beliefs (self-efficacy) †</li> <li>• ↑ positive attitudes and behaviours †</li> </ul>
Argentina										
<b>CYSTIC FIBROSIS</b>										
<b>'Building life skills with cystic fibrosis'</b> [27]	Christian et al. 2006 RCT IIØ (n = 116)	Bandura and Piaget	<ul style="list-style-type: none"> <li>• Child-centred</li> <li>• Individual home-based session (assessing children's current knowledge and how they manage in home environment) PLUS</li> <li>• Group program</li> <li>• Teaching approaches               <ul style="list-style-type: none"> <li>○ Differential learning (content individualised to each child's experience of CF using their own life experiences)</li> </ul> </li> </ul>	YES	Hospital	Middle childhood	Health professionals (unspecified)	YES	2006 (Christian et al.) At nine months compared to controls (usual care):	<ul style="list-style-type: none"> <li>• ↓perceived impact ‡</li> <li>• ↓perceived loneliness ‡</li> </ul>
USA										
<b>DIABETES</b>										
<b>'In Control'</b> [35]	McNabb et al. 1994 RCT IIØ (n = 24)	Bandura	<ul style="list-style-type: none"> <li>• Child-and family-centred</li> <li>• 6x group education sessions               <ul style="list-style-type: none"> <li>○ Separate children and parent groups</li> <li>○ Parents also taught parenting skills</li> </ul> </li> <li>• Teaching approaches               <ul style="list-style-type: none"> <li>○ Directive learning</li> <li>○ Active and experiential learning</li> <li>○ Cooperative and peer learning</li> </ul> </li> </ul>	NO	Hospital	Middle childhood	Health professionals (unspecified)	YES	1994 (McNabb et al.) At three months compared to controls (usual care), children:	<ul style="list-style-type: none"> <li>• ↑ responsibility (insulin)†</li> <li>• ↑ response to symptoms†</li> <li>• ↑ maintaining records‡</li> <li>• ↑ communicating with others †</li> </ul>
USA										

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<b>'Care Ambassador and family-based psychoeducation'</b> [23]  USA	Katz 2014 RCT IIIØ (n = 153)	Unspecified	<ul style="list-style-type: none"> <li>• Child- and family-centred</li> <li>• Family-focused teamwork intervention (split into two age groups 8 to 12 years, 13+ years)</li> <li>• 30-minute session with child and their parent/guardian on the day of their quarterly clinic visit</li> <li>• Teaching approaches                             <ul style="list-style-type: none"> <li>◦ Active and experiential learning</li> <li>◦ Enquiry based learning</li> <li>◦ Cooperative and peer learning</li> </ul> </li> </ul>	No	Hospital	Middle childhood, young adolescents	Lay people	YES	2014 (Katz) There were no significant differences at 12 months in CCSM skills and behaviours, QOL or family conflict  At 2 years, compared to the control group, the intervention group: <ul style="list-style-type: none"> <li>• Greater parental involvement in CCSM†</li> </ul>
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Denotes study quality: + = high quality, Ø = neutral and - = low quality.

Denotes significance †p ≤ 0.05 and ‡ p ≤ 0.01, \* clinical p ≥ 0.05, NS= not significant

Denotes: † increase, ‡ decrease



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**Table 2** Education components broken down by age grouping and specific methods used \*\*NEW Table \*\*

Educational component	Age grouping	Skill/ method/ topic	Selected practice example
<b>1. Structured and sequenced curriculum</b> [16–22, 24–26, 28–36, 36, 39, 41, 44–46]  n=26/30	Infancy	Parent-focused curricula covering all aspects of CCSM, plus stress management.	Detail of an individual curriculum was too long to include in this table – see Ernst et al. [22] p.1154 for an excellent example
	Early childhood	Parent-focused curricula covering all aspects of CCSM, plus stress management, young children from ages 4 years up included in some sessions.	
	Middle childhood	Curricula were generally targeted at increasing children's basic knowledge of their chronic condition and coping strategies. Topics covered: <ul style="list-style-type: none"> <li>• basic information about the chronic condition and children's feelings</li> <li>• recognising and responding to symptoms</li> <li>• treatments and when to seek help</li> <li>• living a healthy lifestyle (e.g. being physically active, eating well, hand-hygiene)</li> <li>• handling problems related to the chronic condition at school</li> </ul>	
	Younger adolescence	Adolescent curricula were aimed at increasing CCSM autonomy and independence. Topics are similar to those covered in the middle childhood age grouping, with increased emphasis placed on problem solving, decision making, and coping with negative impacts of having a chronic condition.	
	Older adolescence	As per information listed for younger adolescence, with additional importance placed on reaching independence prior to transition to adult healthcare services.	
<b>2. Reinforcement strategies</b> [16–22, 24–26, 28–36, 36, 40–42, 44–45]  n=26/30	Infancy	-	<b>Middle childhood example:</b> Colland et al. [41] used reward systems as a way of motivating children towards positive health behaviours. Individuals or small groups were able to “earn rewards”. Each time a child completed their CCSM homework activities then he/she was able to colour in a line on a big poster (sowing a giant thermometer), on which 100 lines were drawn. Lines were also able to be coloured in when group work was completed to a satisfactory level. When 25 lines had been coloured in, then the entire group received a reward, in the form of a small game.  <b>Younger and older adolescence example:</b> In the 2008 intervention by Bruzzese et al. [28], homework activities were given to both the adolescent and caregiver groups. Adolescent homework activities focused on CCSM skills to build self-efficacy, and caregiver homework activities focused on childrearing and positive support
	Early childhood	Take home CCSM action plans (for caregivers)	
	Middle childhood	Homework activities for children and caregivers, written support material for caregivers, children's demonstrations of skills learned, debriefing for both children and caregivers at the end of education sessions, take home CCSM action plans (for caregivers), earning of reward, promotion of /internal incentives, goal setting for children	
	Younger and older adolescence	Homework activities for adolescents and caregivers, teach-back methodology, take home CCSM action plans, and summaries of education sessions (for adolescents), earning of rewards, promotion of internal incentives, goal setting for adolescence	

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			approaches. Homework activities were structured to allow caregivers and children/adolescents to interact in positive ways, and to practice relevant skills together.
<p>3. <b>Active participation</b> [16–22, 25, 26, 28, 30–36, 38, 39, 41, 44, 45]</p> <p>n=25/30</p>	<p>Infancy</p> <p>Early childhood</p> <p>Middle childhood</p> <p>Younger and older adolescence</p>	<p>No direct engagement of children</p> <p>Skills training, hands on participation, use of stories and characters to teach skills (books/videos), observation, modelling (puppets, actors, cartoons), opportunities to practice CCSM skills</p> <p>Skill training, hands on participation, case- based learning, observation, role playing, children's demonstration of skills learned at the end of each education session, interactive game playing to practice decision making, use of stories to initiate discussions around the chronic condition, arts based activities and model building, behaviour modelling (caregivers, facilitators, book characters, puppets), goal setting</p> <ul style="list-style-type: none"> <li>Interventions involving active participation for children in the middle years of childhood tended to have a particular focus on preventing, identifying and controlling symptoms</li> </ul> <p>Skill training, hands on participation, modelling (facilitators), case-based learning, home visits to identify triggers (asthma), role playing, goal setting</p>	<p><b>Early and middle childhood example:</b></p> <p>Detwiler et al. [29] used puppets to actively engage children in CCSM. The use of puppets draws on children's imaginations. Children were asked to identify with the puppet "Huff", who ignores early symptoms, forgets what to do to manage his asthma, and wheezes. Children observe the negative consequences of what happens to Huff because of his poor CCSM behaviours. But, the children are also given a positive role model to observe called "Puff" who is very good at managing his asthma. After learning about asthma management through the use of these puppets, children then get the opportunity to practice their newly learnt CCSM skills.</p>
<p>4. <b>Collaboration</b> [18–22-24, 26, 28–35, 38, 39, 41, 46, 47]</p> <p>n= 21/30</p>	<p>Infancy</p> <p>Early childhood</p> <p>Middle childhood</p> <p>Younger and older adolescence</p>	<p>-</p> <p>-</p> <p>Collaboration between children, their caregivers, and clinicians are encouraged, communication strategies promoted, children given opportunities to directly ask health professionals questions, caregivers encouraged to support and supervise children's CCSM activities, teamwork activities, group processing, sharing of perceptions and experiences, peer group learning</p> <p>Collaboration between adolescents, their caregivers, and clinicians are encouraged, communication strategies promoted, teamwork activities, group processing, increased focus on peer group learning and sharing of experiences</p>	<p><b>Middle childhood example:</b></p> <p>The 1987 study by Evans et al. [30] promoted child to caregiver communication. This intervention (i.e. the "Open Airways for Schools" program) was provided directly to children; parents did not attend. Children's autonomy and independent actions as self-managers were encouraged, with children being given the responsibility to recognise and respond to their own symptoms (whether or not their caregiver was present). The program also encouraged children to provide information to their caregivers to help caregivers make informed asthma management decisions.</p>
<p>5. <b>Autonomy</b> [16-23, 28-34, 36, 38, 41, 43, 44-46]</p> <p>n=20/30</p>	<p>Infancy</p> <p>Early childhood</p> <p>Middle childhood</p>	<p>Infants are completely dependent on adult caregivers for all CCSM activities</p> <p>Young children are completely dependent on adults for CCSM activities; however, some education interventions encouraged children's involvement in simple CCSM tasks (e.g. using an asthma puffer).</p> <p>Interventions become child centred in this age group. Most interventions acknowledged that children could begin to be autonomous for some CCSM</p>	<p><b>Younger and older adolescence example:</b></p> <p>The intervention described by Bruzzese et al. [28] strongly promotes adolescent CCSM autonomy. Autonomy is promoted using two complementary but separate strategies:</p> <ul style="list-style-type: none"> <li>Adolescent sessions focused on prevention and management of asthma – behavioural based program;</li> </ul>

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		activities. Some interventions specifically mentioned that children and caregivers should be treated as equals and partners in the CCSM learning and caring process.	
	Younger and older adolescence	Strong encouragement of adolescents to be autonomous in their own CCSM, where possible. Caregivers encouraged to take on an advocacy and support role (separate caregiver only training provided to teach this role). The need for negotiation and clear CCSM role delineation between adolescents and caregivers was mentioned in some interventions. As above for younger adolescence	<ul style="list-style-type: none"> <li>Parental sessions focused on child rearing skills to support the adolescent's growing autonomy.</li> </ul> Co-joint sessions were not offered, as the focus was on increasing the autonomy of adolescent participants.
6. <b>Feedback</b> [16-20, 28-32, 38, 39, 43-46]  n= 16/30	Infancy	-	<b>Older adolescence example:</b> Mammen et al [34] integrate feedback mechanisms into their intervention. After CCSM activities were modelled by facilitators (e.g. inhaler techniques, use of peak flow meters and spacers, decision making during asthma attacks), adolescents practiced CCSM skills with feedback being provided on the spot until fluency was attained.
	Early childhood	Encouragement given when good CCSM behaviours or knowledge are demonstrated (positive approach), timely feedback	
	Middle childhood	Symptom diary interpretation, encouragement given when good CCSM behaviours or knowledge are demonstrated (positive approach), timely feedback	
	Younger and older adolescence	Opportunities to practice CCSM skills and get feedback during education sessions, caregiver praise, timely feedback	
7. <b>Multiple exposures</b> [21, 22, 25, 28, 30-32, 38, 39, 46].  n= 10/30	Infancy	-	<b>Middle childhood example:</b> The papers by Ernst et al. [21] and Ernst et al. [22] describe the MoDuS program ( <b>Modulares Schulungsprogramm</b> ). This program exposes children to CCSM related information and skills multiple times to help them internalise the information. Multiple exposures were coupled with giving children adequate time to practice doing the CCSM skills they had learned to do. In this program, feedback was also given during practice rehearsals to ensure that children retained the correct information. The MoDuS program is a generic CCSM program that can be used across a variety of conditions due to similarities in the need to monitor symptoms and manage treatments [22].
	Early childhood	-	
	Middle childhood	Repeated demonstrations and multiple opportunities to practice newly learnt CCSM skills	
	Younger and older adolescence	Repeated demonstrations and multiple opportunities to practice newly learnt CCSM skills	
8. <b>Problem solving</b> [11, 19, 20, 23, 26, 33, 34, 36, 42]  n= 8/30	Infancy	-	<b>Middle childhood example</b> Lewis et al. [33] put children in the "driver's seat", emphasising that asthmatic children could take control of their condition (this represents a simple paradigm). An analogy was drawn between maintaining health and safely driving a car. Obeying traffic light signals was a key message, i.e.
	Early childhood	-	
	Middle childhood	Use of simple paradigms to communicate messages, colour coding of key concepts, practical demonstrations, collaborative discussions between children and caregivers	

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	<p>Younger and older adolescence</p> <p>Practical demonstrations, collaborative discussions, individualisation where possible (e.g. through use of CCSM assessments and one-on-one sessions were individual problems and challenges could be discussed)</p>	<p>green for go, yellow for caution, and red for stop. Children controlled their asthma by using the colour system:</p> <ul style="list-style-type: none"> <li>• Green coloured medications indicated keep going and prevent symptoms</li> <li>• As mild symptoms develop, it is time for children to slow down and take a more cautious approach using medications coloured yellow</li> <li>• If/when severe symptoms occur it is time to take red medications to stop the asthma episode</li> </ul>
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**Table 3** CCSM outcomes for children's educational interventions with age/developmental considerations compared to usual care

Children's	Number of studies reporting significant improvements when compared to usual care	Associated references
<b>CCSM skills, abilities and behaviours</b>	11	[18, 20, 23, 30, 31, 33, 35, 40, 41, 44, 46]
Knowledge	10	[16, 18, 22, 24, 29, 34, 36, 37, 41, 42, 46]
Cooperation/communication	5	[23, 30, 31, 33, 35]
Sharing in decision making	3	[30, 31, 35]
Monitoring and responding to symptoms	5	[20, 28, 33, 35, 39]
Managing the impact of the condition	4	[27, 33, 36, 41]
Self-efficacy	8	[16, 18, 20, 26, 30, 34, 44, 46]
Quality of life	2	[16, 44]